The Role of Housing In Management of Chronic Disease

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SUMMARY A chronic patient's environment becomes an important part of his life, and can actively be used in his treatment. This article describes ways of involving the patient's surroundings in a total management plan.

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THIS IS AN ATTEMPT to look at the architectural design of housing as an active participant in the day to day management of chronic disease. In this study, chronic illness is considered to be any illness or disease by which an individual is incapacitated to any major degree either continually or intermittently over an extended period of time. Management of chronic disease is taken to mean the control of such illness so that the patient may enjoy the maximum mobility, well-being and choice of activity that is possible for him.

In looking at some of the different kinds of disability that may be involved, diseases might be classified by length of illness, age at onset, intensity of nursing care required, days lost from work per year, degree of incapacitation, etc. Since our subject is housing, we shall classify it in terms of the length of illness and degree of incapacitation; for example, bed patients (immobile), bed patients (partially mobile), wheelchair patients, intermittently incapacitated individuals, to those who lose several weeks off work each year.

In the general housing field, controls which are a public health responsibility include 1. economic availability of suitable housing accommodation to avoid overcrowding (doubling up of families in dwellings and of persons per room) and to cope with anxiety caused by financial insecurity if the wage earner loses his job; 2. building inspection to ensure safety of structure and wiring; 3. maintenance of pest control to avoid the spread of disease and danger to small children; and 4. insurance that water, electricity and other essential services are always available despite ability to pay.

If the management of chronic illness is to be even partially dependent on home treatment then access to community facilities is important, and so are the doctor's house calls. Many doctors may deplore the architectural obstacles of patients' homes, like stuffiness, dust, accident hazards and inconvenience, yet how many doctors would be able to advise the family on the economical rearrangement of floor space, the construction of built-in furniture, the removal of a partition, installation of a different lighting system, re-arrangement of levels, windows, maximum utilization of sunlight, elimination of draughts?

Perhaps it would be possible to visualize a time when a medical team would include the services of an architectural psychologist in discussion of the patient's total environment for each case of chronic illness. Specialists in hospital design have found that the scope for cooperative planning between architects, doctors, other medical and support staff and patients is broad and relatively unexplored.

Critical Factors Related to Architectural Considerations

If the patient is to be confined to his bed for a certain period, then the one most important factor in his physical and psychological environment is *time.* It will affect him physically in terms of stiffness, fatigue and pain, and psychologically in terms of boredom, monotony, frustration and despair.

A second critical factor is *immobility.* 'Environmental therapy' must vary with the prognosis, and his expectations of regaining certain areas of mobility. Where the expectation is low, emphasis might be laid on mobility around him with the least possible fuss, so as not to focus attention on his disability. Where prognosis is good, his environment might be designed to be at first supportive of his handicap in keeping with the intensive care he has been receiving, but with an increasing incentive to independent action. For example, a window with an interesting view, being just too high up to enjoy while lying flat in bed would be an incentive to sit up, and stand up.

The architectural environment cannot in itself effect a cure – far from it! Each hurdle to be attempted by the patient must be achieved through the combined efforts of the environmental design and the patient's will, in addition to all the medical aids.

Amongst basic architectural considerations might be the control of infection. This includes some of the design principles which are fundamental to hospital planning, but with a difference. Hospitals require materials which are hygienic, enduring, simple, capable of mass production, convenient for a large and changing staff of doctors, nurses,

therapists, technicians and cleaners. They should also be as esthetically pleasing as possible to an endless number and variety of patients. The environment of the chronically ill patient must also be hygienic and enduring, but it needs to be esthetically warm, highly individual, flexible, and wherever possible manipulable by its principal occupant, the patient. Volumes have been written on design and specifications for the hospital operating room. It has become a science of specialists, and rightly so, since the greatest care is required for protection from not only infection, but electric shock, fatigue and surgical error. The design of intensive care units, isolation wards and ORs is for an occupancy of short term and very short term duration.

This point is made to emphasize the fact that these maximum sterility conditions increase the danger of infection from outside contacts. If continued over a long period of time, the sterile environment will counteract the natural immunization against relatively harmless germs which normal persons encounter every day. For patients, it is important in the long run to keep the body fighting. Therefore, the environment of the chronically ill should be as 'normal' as possible, yet hygienic and more easily cleaned and changed or modified than average.

To go from some simple basic concepts to more complex areas for study, some of the considerations for architectural participation might be as follows:

1. Consideration of adverse effects of time upon perception, and how this may be met simply and economically in the structure of the environment.
2. The effects of strain from inefficiencies in the home environment, and how this may be avoided.
3. The effects of strain from financial insecurity and fear of involvement in expensive alterations to the house.
4. The effects of environmental inefficiency relayed from the patient's attendants to the patient himself.
5. The possibilities of positive incentive in the environment itself (relationship to windows, furniture, bathroom facilities, etc.).
6. Some of the positive aspects of change, in their effect on the patient's morale.
7. The need for differing kinds of change – flexibility in planning to allow for change in the patient, progress, growth and challenges in differing degrees as required.
8. The need for communication, by telephone, writing, or face to face. The architectural psychologist must concern himself with the avoidance of deterioration, depression and discouragement on the part of the patient. He must allow for the fact too, that if the person taking care of the patient has reason to be discouraged or frustrated by the inefficiencies and inconveniences of home care, she will pass on her frustration to the patient and delay or baulk his progress if not actually reverse it. So he must design for home care with maximum convenience and optimism and a minimum of drudgery and discouragement.

In the avoidance of deterioration, some of the relevant factors are observation, vigilance, flexibility and change. Deterioration, when and if it does occur, can be met and dealt with if continual observation of the patient is facilitated, in such a way that actual deterioration may be understood in relation to a variety of conditions without side-effects from boredom, discouragement or panic. This same variety of environmental conditions may be used to conceal from the patient himself the expected ill effects of physical deterioration.

Every individual who has either an incapacitating or a chronic illness also has some particular psychological problems relating to the limitations which the illness imposes. Every individual, even those in good health, has his special psychological needs. The chronic patient already has an army of scientists and technicians controlling his medication, diet, activities and rest. Frequently they have to work against severe limitations which exist in the patient's home environment – inconvenient plumbing facilities, difficult layout, poor ventilation, over-furnished areas, small rooms, unsuitable movement or communication patterns and limited scope for change. Why should his environment not be given the same detailed study as his medication, which is changed or modified according to its effects?

The family doctor knows how seriously and intimately a patient's environment can influence his recovery – especially in the psychological acceptance of a long-term illness. The security of the family's presence is recognized as sometimes more vital to survival than the hygienic sterility of a hospital. In the modification of homes to accommodate the chronically ill, it frequently happens that either the patient or his nurse, or both, must adapt to the conditions of the structure rather than the other way around.

There is no suggestion that extravagant environmental revisions should be made simply to keep the patient happy or merely for greater convenience, such as the installation of a bell in the patient's room, a dumbwaiter to carry trays up one storey or a new washing machine or dryer. Each of these items may be good in itself, but it may not be the most important for the patient's well-being.

Analysis of the Patient's Environmental Needs

Suppose for a moment that we consider the impact of his environment as an integral part of a patient's diagnosis. Then an analysis of his environmental needs, in terms of his physical and psychological needs, would become a part of his program for therapy, especially after his return from the hospital. At this point his needs are the opposite of all that was so efficient in the hospital. Consider the installation of a bell by the patient's bed: if it is important for his ultimate improvement that he train himself to be as mobile and independent as possible, then the installation of the bell will do him more harm than good.

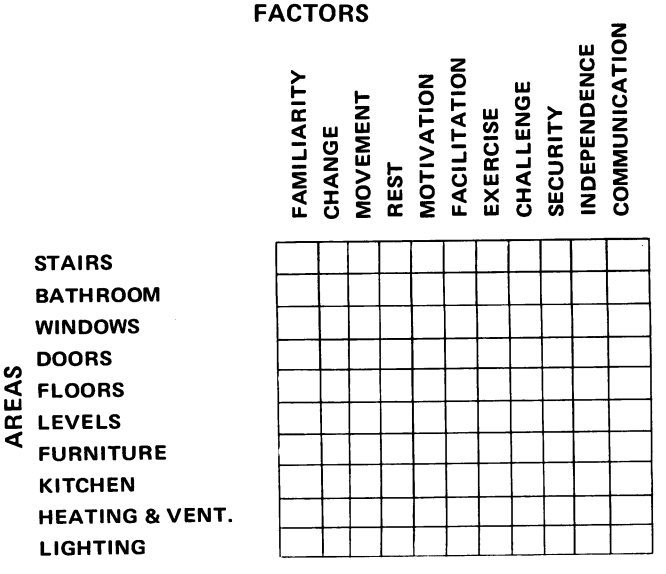

Figure 1

A completely integrated planned program may be less expensive in the end – one which gives first consideration to the patient's welfare and at the same time takes into account the ease of services for doctors and nurses.

The patient's well-being will include fulfillment of his long-term needs for variety, change, growth, challenge and motivation. These will not be met merely through the installation of a new washing machine. The patient's response to a new challenge may render the elaboration of the washing facilities less necessary in the long run. Who knows?

Because of the initial shock condition which accompanies adjustment to most serious chronic disease, one might begin by giving the patient an environment which makes life seem worthwhile. Many patients have daily routines of bathing, eating, medication and physiotherapy – any or all of which may be difficult or unpleasant. While he is in hospital he probably has family or other visitors to provide diversion and encouragement as a change from this routine. How does he fill this gap in company and communication when he gets home? Perhaps he doesn't want company – but it keeps him in touch with the world. Many people are eager to visit someone in hospital. It is an appropriate thing to do. But will they continue to visit the patient over an extended period of time after he goes home? Some incentive to visitors might be built into his architectural environment, if this seems appropriate to his personality and situation. (Diabetics, for example, who live alone require support to maintain morale, diet, meal preparation and new habit learning.)

Architectural detailing alone will not do much for the patient. Housing is for people, and architecture reaches its finest achievement in its combination with human use and activity, like the members of an orchestra and their instruments.

Where the patient's mobility is restricted, visitors should be encouraged to keep coming with:

1. Relatively easy access, perhaps a place to park their cars – perhaps an automatic door opener, if this is appropriate.

2. Space for them to sit down in a comfortable position in relation to the patient – not to stand by his bed, or sit behind his head or below the foot of the bed, half out of sight, as happens sometimes in hospital.

3. Enough air and ventilation to accommodate several people in the patient's room if this is what he needs, so that two or three people may visit occasionally without making the room stuffy, and so that odors of the sick room do not turn the guests away.

4. Perhaps his environment might have something for visitors to talk about over the long tiresome weeks. (Many guests are well-meaning but embarrassed conversationally). Why not something changing, something to attract them, a developing interest they may share with the patient?

5. There may be something that the visitor can help the patient with from one visit to the next, e.g. help him to the window where he can see out, or take him for an outing in a wheelchair. Does his space allow for this, or must his visitor be a Goliath in order to offer such service?

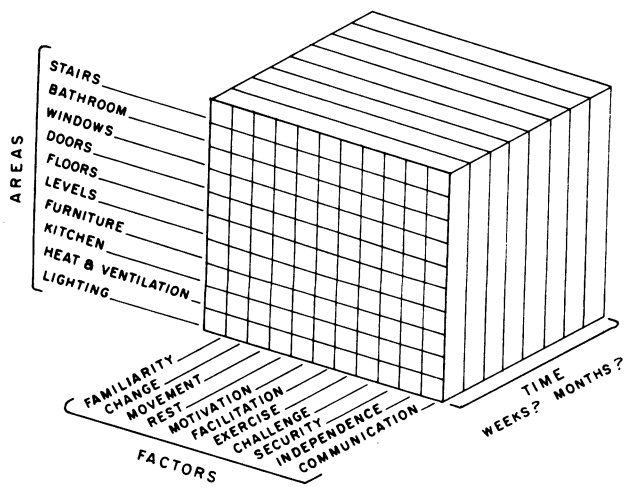

Figure 2

An Approach to the Problem

These points give a lead as to how the study may be tackled. They suggest an analysis of the needs associated with any particular individual suffering from a long-term illness which is to be controlled in the home. These might be listed and tabulated in some form. The actual analysis for any individual would cover only his own needs based on his age, type of illness, degree of incapacitation and prognosis. His plan will be based on a matrix which matches architectural areas with factors in health improvement such as that shown in Figure 1.

When this two-dimensional matrix is projected onto a third variable of *time,* then we have a three-dimensional model on which to base a fluid environmental prescription. The cells within the matrix will become channels of thoughts and ideas over time, and may be used additionally to record progress and change as well as to formulate plans. Within these channels of thought the patient himself will often be able to plan his own future and follow his own progress, depending on his age and the type of illness. The purpose of the matrix is to guide thinking into areas which have not been examined, and then to explore the development of an idea over time.

Many chronic illnesses have their onset close to middle or later age. One family physician has noted that in the case of older patients, the single factor of familiarity in home surroundings will counteract the effects of any number of inconveniences and even health hazards. In an older patient, this factor may be the most important one in the matrix.

The same doctor has observed that the younger the patient, the greater the contribution of the environment in the battle for health. For the youngest patients, the model may be very full of thoughts and ideas to be tested in practice, especially in the beginning. The child diabetic has been a source of learning about hereditary factors of diabetes as well as control and limitations of the disease. He may also be the greatest source for learning about the strengths of environmental influences.

An example of the development of the matrix shows the spontaneity and diversity of ideas and comments that this method will allow. The first row might look something like this:

Stairs

Familiarity: this is especially important for their *location* to avoid accidents or confusion, especially at night.

Improvements: should be well lighted, should be appropriate to patient's needs, may benefit from carpeting, need

a good handrail – should they have slip-proof treads?

Movement: short flights may be needed, including a space to sit down.

Rest: patient may not need to climb stairs to rest; is there some other alternative?

Motivation: if it is important to climb stairs they can be made beautiful and interesting, with photos and pictures hung all the way up.

Facilitation: use of stairs may be avoided by living all on one level – a ramp might be installed.

Exercise: may provide a source of exercise and challenge, with measure of achievement. Should be included in medical prescription, especially in heart cases.

Challenge: may be means of access to a desired objective.

Security: how safe are they? Also some people cannot sleep on the ground floor, but feel they must go *upstairs* to bed at nights. This can give a feeling of security.

Independence: the mastery of stair climbing after a period of immobilization is a key to independence of action in everything.

Communication: should not depend on the patient having to go up or down stairs – *telephone* should be on the same floor. Means of simplifying access for visitors and attendants important too.

Conclusion

The psychology of the patient's environment is an area worth exploring. The element of *time* is the principal challenge and the factor of *change* makes it fluid and versatile. How can we turn the restrictions of chronic illness into facilitators for growth? What constitutes a challenge to the patient and how great should that challenge be? It is through our environment that we understand both ourselves and our lives. These are the basic design data for the architect and the psychologist in designing for health and for growth. ◀

Acknowledgement

I would like to acknowledge the assistance of Dr. J. N. Rushforth of Ottawa, who read the manuscript and offered helpful advice and suggestions, especially on basic concepts and specific illnesses.

QUOTE

I knew that suffering did not ennoble; it degraded. It made men selfish, mean, petty and suspicious. It absorbed them in small things . . . it made them less than men; and I wrote ferociously that we learn resignation not by our own suffering but by the suffering of others.

W. Somerset Maugham (1874-1965)
The Summing Up, Sect. xix